THE PRESS AND AIDS*

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SOMETHING about medicine appears in the news almost every day, and that may seem new, yet it is not.

From almost the founding of this country, medical developments have made news in the United States, particularly those that have affected public health. In 1799, for example, Dr. Benjamin Waterhouse, upon learning about Dr. Edward Jenner's smallpox vaccination technique, said: "As the ordinary mode of communicating even medical discoveries in this country is by newspapers, I drew up the following account of the cow pox, which was printed in the 'Columbian Centinal' March 12, 1799."

The *Columbian Centinal* was a semiweekly newspaper published in Boston. Unfortunately, it has gone the way of so many other publications since then—not to speak of smallpox.

Smallpox is just one of thousands of medical topics that have been in the news over the years. Today it is AIDS that is in the news every day. It has been there, at periodic intervals, since it was first detected as an unnamed disease in 1981.

What was said about AIDS, how often, and when, have been sources of continuing controversy since the first stories were published. And undoubtedly the controversy will continue because controversy is guaranteed when the world is faced with a deadly new epidemic of uncertain magnitude from a viral disease that cuts across society in a way few other diseases have.

Clearly, AIDS and the press is a fitting subject for a meeting devoted to controversies of contemporary issues in infectious disease in the current economic and clinical environment. All of us have much to learn about the reporting of such matters.

The seemingly endless list of controversies raised by AIDS are ones that once were restricted to discussions among small groups and well out of the public eye. With AIDS, they make headlines. Why?

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To begin to answer that question, we must recognize the revolution that has occurred in the financing of all aspects of medicine, a revolution that over the period of just a few decades has transformed medicine from a private entrepreneurial system to a public institution.

No longer are the Rockefellers and other philanthropists the chief patrons of medicine. Today the public is the major patron. The public pays a major share of the costs of medical care, medical research, and medical education.

That means the government has a major voice in policies that once were strictly private and that all aspects of medicine have become political, subject to review by the institutions of government. Those are points that many physicians do not like, although the academic community fought for that very expansion of the federal involvement in medicine.

Journalism covers medicine because it is a subject inherently interesting to so many people. Also, because public expenditures require public accountability, journalism covers medicine the way it covers the State Department, the Pentagon, and all other government institutions. Under such conditions, however, the press cannot be the simple recording secretary and public relations officer for science that many scientists want the press to be.

This background explains why in recent years the public has had more of a chance to see medicine and public health at work, to gain some insights into the nature of discoveries, and at the same time to learn that discovery is a flawed process influenced by human nature as much as esoteric knowledge and scientific discipline. The background also points out that scientific reports of discoveries of the causes of other recently recognized diseases have sorely lacked much of the human dimensions, politics, and other contributory factors.

Today I would like to focus on an area of AIDS and the press that has not been given the attention it needs. The subject is medical journals. But before doing so I want to make a few other points about AIDS and other recently recognized diseases.

When legionnaire's disease was discovered in 1976—during America's 200th birthday celebration among a group of men after they returned to their homes from a state American Legion convention in Philadelphia—legionnaire's disease posed a clear and present danger: how safe was it to travel to Pennsylvania?

Bear in mind that one million people were about to travel from all over the world to Philadelphia for a Eucharistic Convention. Remember, too, the discovery of legionnaire's disease came when America was poised for an epidemic, one predicted by the United States government. The epidemic was

swine influenza. United States public health officials had persuaded Congress and the president to manufacture enough swine flu vaccine to immunize every American. But when the epidemic did come, it turned out to be legionnaire's disease, not swine flu.

Someone who read the scientific reports of the discovery of the bacterium that causes legionnaire's disease and who did not consult other articles might believe the implication that the cause was clear from the beginning of the outbreak. The reader would not have learned much about the blind avenues scientists went down, the public concern about swine flu, toxins, and other public health considerations.[1]

Another so-called new disease, toxic shock syndrome, was actually an old one, staphylococcal scarlet fever, in a new guise. Toxic shock syndrome presented as a consumer problem for women because of a link to a product, tampons.

The presentation of AIDS was different, and it put journalists in a quandary.

Journalists, like public health officials, have had to avoid alarming the public and creating hysteria while also reporting the news. At the same time, news organizations must jealously guard their independence and not become an arm of the government. Remember, the government is the source of all official public health data. Remember, too, there are some in our society who believe the numbers of AIDS cases is purposely set low to diminish the impact of the epidemic.

A key journalistic task in the case of a new disease is to report developments as they occur. It is an educational function, but one that differs from formal courses. Journalism does not have captive audiences as do schools. News organizations compete for readers and viewers and depend on them for their economic survival.

The AIDS and the press story has had its share of unusual twists.

For one, the media have been criticized for not explicitly defining early enough, and well enough, how AIDS is transmitted—and for not defining precisely the phrase "bodily fluids." The same criticism has been directed at public health officials.

I view the criticism as a favorable development.

Recall that only a few decades ago a radio network refused to broadcast the surgeon general of the United States Public Health Service's talk when all he wanted to do was *mention* syphilis. More recently, the media have talked about sexually transmitted diseases. But the media generally have not used

explicit language to describe how syphilis and gonorrhea and herpes, for examples, are transmitted.

The criticism for the delay in doing so with AIDS may leave us with one beneficial legacy—the greater use of more graphic language in medical articles. But that is not a certainty because sex education remains a hot political issue.

We live at a time when the networks will not accept ads for oral contraceptives.[2] We have had flaps over their acceptance of advertisements for condoms. Another point: AIDS has not been the only medical story in the news.

My first story about AIDS was in July 1981. It was as early as any. Yet I had intended to write it even earlier.

But those plans were thwarted by an assignment to cover the assassination attempt on President Reagan in Washington. Then, as I was about to get back to AIDS, I was sent off to cover the attempted assassination of the pope in Italy. There, not to make things easy, I broke both elbows!

Then there was competition from the implant of permanent artifical hearts. What some people may have seen as excessive coverage of artificial hearts to me was a good example of showing the public clinical research at work on an advance that, if successful, would have an enormous medical, economic, social, political, and ethical impact on society—an impact that could have rivalled AIDS in many respects.

Still another point concerns journalistic resources. Should major news organizations assign reporters full time to the coverage of AIDS? And how many? If you believe that they should, then do you believe that news organizations should assign someone full time to cover heart disease, which after all, is the nation's leading killer? And cancer, the second biggest killer? Should the number of reporters covering a disease reflect the number of cases or deaths it causes. Where do you draw the line?

My interest is infectious diseases, and I spend as much time as I can on AIDS. But I cannot spend full time on AIDS.

Any discussion of medical journalism would be incomplete if it excluded the role of scientific journals because they clearly are key elements in the theme of this meeting. Yet I suspect that when most of you think about AIDS and the press, you focus on newspapers, magazines, and radio and television—and omit scientific journals.

But because scientific journals are clearly a crucial aspect of AIDS and the press, I shall draw attention to their role in the remainder of this presentation. And in the spirit of this meeting, I shall be provocative.

Leadership is one of the many roles medical journals play, and one of the most important.

Journal editors have exerted that leadership by crusading about various social, ethical, and economic problems in medicine. Yet I can recall only a rare editorial about AIDS from a medical journal editor.[3] Editors who have been so outspoken about other ethical issues have been silent about the ones relating to AIDS and the medical profession.

Why, for instance, has it been left to the *New York Times* and other newspapers to write editorials on the medical profession's obligation to care for HIV infected individuals? Why the silence from medical journal editors on such an important issue?

One of the peskiest issues in medical journalism concerns peer review, principally because in recent years many medical journal editors have made so much of it.

Many scientists, in turn, have responded almost reflexively and religiously, in blind faith, without really knowing what peer review means. It is hard to know because there is no standard definition of peer review. Much if not most of what appears in so-called peer reviewed journals is not peer reviewed, and *Index Medicus*, the standard international reference, cites both peer reviewed and nonpeer reviewed articles without distinguishing among them.

These are among the reasons why the first conference anyone can recall on peer review in medical journals will be held in 1989, sponsored by the American Medical Association.

My aim today is not to attempt to destroy peer review, but to point out that the medical profession is making far too much of it, with the resulting erosion of the credibility about which Merle Sande spoke. As I see it, peer review is not the scientific process that many claim it is. Rather it is a standard editorial function based on expert technical criticism that physicians put under the guise of a pseudoscientific term.

Elsewhere in journalism, peer review is called vetting. The quality of vetting or peer review varies with the type of report, the person, and even the day that person carries out his assignment.

Remember: opinions of peer reviewers are not binding on journal editors. Thus, the decision to publish a paper in a scientific journal or to reject it is far more subjective and editorial than scientific.

Fine, we say. Peer review improves accuracy. Yes. When peer review lives up to its billing, it can serve society well in the sense that it prevents the publication of worthless science. But there is no guarantee of that; look at the

fraudulent papers that have passed peer review.

There is another point, illustrated by the following anecdote. It was a leading federal AIDS researcher, Dr. Anthony Fauci, who now heads the National Institute of Arthritis and Infectious Disease, who suggested the possiblity of catching AIDS through casual contact in an editorial in a peer reviewed journal, the *Journal of the American Medical Association.* That editorial accompanied a peer reviewed article that said "Our experience suggests that children living in high-risk households are susceptible to AIDS and that sexual contact, drug abuse or exposure to blood products is not necessary for disease transmission."[4]

In May 1983, in an editorial accompanying several papers on AIDS in homosexuals and in children, Dr. Fauci said: "First, it is possible that AIDS can be vertically transmitted. Perhaps even more important is the possibility that routine close contact, as within a family household, can spread the disease. If, indeed, the latter is true, then AIDS takes on an entirely new dimension."[5]

The American Medical Association issued a news release that highlighted these statements. The media were criticized for reporting them, even though they included statements by a key government public health AIDS worker released by the largest medical organization in the United States.

In one sense, not to have reported the story could have been perceived as censorship.

Most pertinent, neither Dr. Fauci nor the *Journal of the American Medical Association* has corrected Dr. Fauci's statement although the journal published a letter from two physicians who said: "It is too early to suggest that AIDS is acquired by household contact without substantial evidence to support such a claim."

Nevertheless, in January 1984 Dr. Fauci said in another peer reviewed journal, the *Annals of Internal Medicine:* "There is no evidence that the acquired immunodeficiency syndrome can be transmitted by routine household or social contact.[6]

So what should journalists believe when the same public health official makes decidedly different statements in two peer reviewed journals? When does the second statement overtake the first if the first is not corrected? Or was the first correct and the second in error?

Consider also the editorial that Dr. Joseph Bove wrote in the *New England Journal of Medicine* when that journal carried an early report on the transmission of the then postulated AIDS virus through blood transfusions.[7] Dr. Bove did not cite in his *New England Journal of Medicine* editorial an earlier

editorial he had written in another journal that scoffed at the evidence for transfusion AIDS.[8] Reversing an opinion is admirable. But reversing an earlier opinion without citing an earlier reference does not deserve applause. It also raises questions about the quality of peer review, a subject that has received less attention than it should if journals place so many restrictions on what scientists can say before their work goes through the peer review process.

The process of peer review can serve society poorly if editors, in a desire to avoid making errors, reject novel ideas. Remember that Edward Jenner, the scientist who developed the only vaccine that has eradicated a disease, published on his own after his paper on smallpox vaccine was not considered by his peers. Would someone else have developed a smallpox vaccine if Jenner had not persevered? We do not know how many similar anecdotes will turn up in AIDS.

Luc Montagnier told me that he had great difficulty getting his first paper published. Even after it was published, leaders criticized the peer review system for letting it through, and few believed him for a year. Moreover, one of the referees of the French paper was Dr. Robert Gallo, who one year later claimed that he discovered the AIDS virus.

The validity of the Pasteur Institute's work has held up, much more so than the views of the critics.

Consider also the report last year in a peer reviewed journal, the *American Journal of Tropical Medicine and Hygiene,* of the discovery of a hitherto unknown virus. It was identified in samples from AIDS patients with Kaposi's sarcoma.[9] The announcement by the scientist appeared on the "Editor's Page," with a promise that the researcher would go on to characterize the new virus. Yet more than a year has passed and no further details have been published in that or any other journal.

Are we being kept from learning the details of a virus that may play a crucial role in AIDS? Or was it, as often happens in science, a claim that failed to hold up and for which clarification did not occur because follow-up reports were either not submitted or were rejected by editors? A weakness of both scientific and lay journalism is the bias toward selecting reports of positive findings. Yet in science it is often as important to know a negative result as a positive one.[10]

There is also alas a relative lack of follow-up of positive findings reported in these journals. Many so-called positive findings are not confirmed, yet the reader who relies on the scientific literature system would not know it be-

cause of failure to report follow up studies that do not confirm the original findings.

Further, we know little about the costs, if any, to society of rejections and of the delays in publishing other papers.

I emphasize this point because the system that journal editors have created and the academic community has so fully supported is one with little accountability.

It is impossible for readers to know what has been submitted to a journal and rejected, and what was not submitted at all. In this regard, errors of omission can be as important as those of commission. But there is no way independently to check. And when most of the research is taxpayer supported, that is a critical problem.

What about the delays created by journals that take months to review research papers and then reject them for editorial, not scientific, reasons? What impact does that have on public health? Early papers on pediatric AIDS, we are told, were rejected by peer reviewed journals for one or another reason.

At times, journals have put their self-interest, which includes circulation and profits, ahead of their concern for public health. One journal rejected the first paper on transfusion AIDS because the discoverer, in putting public health concerns ahead of his personal interests, published it in the *Morbidity and Mortality Weekly Report*.

I will close by relating an amusing anecdote of how this affects our work, about what you read, and when.

Just before the first papers reporting on HTLV-1 as a purported cause of AIDS were to be published, a network news broadcast focused on Dr. Gallo and the National Cancer Institute's role in the development.

The public relations officer from the Harvard School of Public Health called. It was early evening. Max Essex, a coauthor of these papers, wanted to talk, the public relations officer said, and he made sure I had Essex's home phone number so I could interview him that night.

I spent the entire evening, until about midnight, ringing Essex's number. It was constantly busy. I presumed that he was talking to other reporters and that I was having bad luck in getting through amidst my interviews with other scientists about the development. When I reached him about midnight, I learned that my presumption was incorrect. Dr Essex had taken the receiver off the hook. Before I had a chance to reach Dr. Essex, Dr. Gallo had called and told him not to talk to the press, Dr. Essex said. But in the interval no one

called me back to say the interview was off. Ironically, as it turns out, what was being protected were reports in a peer reviewed journal, *Science*, about the wrong virus link to AIDS.

I have focused on peer review and medical journals because the issue affects far more than AIDS. The economics of medical journal publishing, which involve profits derived from taxpayer supported research, make it an important part of the controversies of contemporary issues in medicine.

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